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ABSTRACT

Reauthorization of P.L. 99-457, which became the Individuals with Disabilities Act Amendments of 1991, mandated the establishment of the Federal Interagency Coordinating Council (FICC) in order to help mobilize all available resources to assure appropriate services for the nation's infants and young children with disabilities and their families. This issue of the "Early Childhood Bulletin" describes the work of parents on the FICC. Each parent on the FICC has a work plan to reach out to State ICCs (SICCs), state ICC parents, and other parent leaders in the states assigned to them. In addition to introducing these parents, this issue describes the history and mission of the FICC and reports on the work done by FICC parents in a meeting with state ICC parents held in Washington, D.C. in November 1996. The paper describes two major concerns discussed by the group as a whole, including: (1) issues of confidentiality; and (2) issues of support for parents serving on state and local councils. Also included are an FICC overview (Connie Garner), a short biographical sketch of Judith E. Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services, and comments by Congressman Major Owens on the importance of Parent Training and Information Centers. (SG)

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EARLY CHILDHOOD BULLETIN

FICC PARENTS REACH OUT

SPRING

1997

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Coalition Quarterly

EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Spring — Prepared by the Federation for Children with Special Needs Parent Component Staff of NEC*TAS — 1997

FICC PARENTS REACH OUT

*This edition of the Early Childhood Bulletin describes the work of the parents on the Federal Interagency Coordinating Council. As of March 15, 1996, there are currently seven parents serving on the council and each has a work plan to reach out to State ICCs (SICCs), state ICC parents, and other parent leaders in the states assigned to them. In addition to introducing these parents to you, this issue of the bulletin describes the history and mission of the FICC and reports on the work done by FICC parents in a November meeting with state ICC parents held in Washington, D.C. as part of the NEC*TAS Combined Meeting, November 1996.*

Parents serving on their state Interagency Coordinating Councils gathered in Washington, D.C. in November 1996 to hold an annual meeting sponsored by NEC*TAS as part of the Combined Meeting. This year the focus was meeting the FICC parents. The FICC parents wanted to hear from state parents what topics and issues were of concern to SICC parents which were being discussed in the ICCs and by other parents in their states. Parents met in small groups by regions (see list of FICC parents and the states they serve on the insert of this Bulletin) and then reported to the whole group. The two major issues discussed by the group as a whole were confidentiality and the need for support to serve on these councils. These topics are described in more detail below, and other issues discussed in small groups are listed.

Confidentiality

Many parents reported that they felt confidentiality is being used as a barrier to parent-to-parent networking. Parents try to meet other parents in the program and are told they cannot get their names because it breaks confidentiality with them. Another parent reported she was denied access to a videotape showing an environment in which her child might be placed because the agency was inappropriately guarding the identity of the other children on the video. Several solutions to overcoming these barriers were suggested, among which included programs asking parents if their name can be released for networking or public awareness purposes. At the same time, parents present at the meeting noted the need for respecting the privacy of parents who do not wish their name to be made public. The FICC parents will explore these issues further by collecting more stories from parents, discussing this issue in the Family Empowerment Committee, and reporting back to the state parents on what they have found.

Support for parents serving on state and local councils

Parents need both financial support to cover the expenses incurred for attending meetings and moral support and training for learning to be effective members of their councils. This is a recurrent theme discussed frequently when parents meet. [*Ed. Note: A future edition of Early Childhood Bulletin will specifically address the issues surrounding financial support for parents; in this issue, the specific needs for training requested by parents is outlined on page 4.*] The FICC parents recommended requesting an earmarked fund at the federal or state level for parent reimbursement so that parents are not hostage to local politics. This will be explored further in the Family Empowerment Committee.

Other issues raised

Other recurrent themes expressed in small groups included: the impact of managed care on eligibility and service integration; parents as respected and equal partners; transition as a stressful experience; the need for leadership training for ICC parents and increased training for professionals in principles of family centered care; the use of "menu of services" which is contrary to the principle of the individualized family service plan; and the suggestion of having a parent be paid to participate on the monitoring team of OSEP visits.

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The Family Empowerment Committee of the FICC will follow up these discussions with the parents who participated in these sessions to gain a better understanding of the issues and to develop documentation of where and how these issues arise. The FICC parent representatives will then develop recommendations for policy changes on these issues through the committee process and report back to the FICC and to state parents on recommended actions.

The Federal Interagency Coordinating Council

by Connie Garner, Executive Director, FICC

History

With the passage of the Education of the Handicapped Amendments in 1986 (P.L. 99-457), Congress enacted a national program to expand and improve early intervention and preschool services to infants, toddlers and preschoolers with disabilities. Two programs established under this legislation are Part H—the Early Intervention Program for Infants and Toddlers with Disabilities; and Section 619—the Preschool Grants Programs. Both programs provide financial support to States for the planning, development, and implementation of services for young children with disabilities.

Although early intervention and preschool services have been a part of Federal efforts for years, these programs challenge the Nation to improve and expand those services so that the policy goal of a statewide, coordinated, interagency system of services can be achieved. To assist in this effort, one of the provisions of Part H is the establishment of State Interagency Coordinating Councils (SICC) to advise and assist the State lead agencies in achieving a coordinated service delivery system.

Recognizing the interagency nature of this enabling legislation at the Federal level, the U.S. Department of Education and the U.S. Department of Health and Human Services signed a Memorandum of Understanding endorsing the establishment of a Federal Interagency Coordinating Council (FICC) shortly after the original authorization of P.L. 99-457 in 1987. The FICC was established to mirror the role that Congress stipulated for SICCs including the mobilization of all available resources to assure appropriate services for the nation's infants and young children with disabilities and their families.

Reauthorization of P.L. 99-457, which became the Individuals with Disabilities Education Act Amendments of 1991, statutorily mandated the establishment of the FICC and expanded its membership to include: (1) the Departments of Interior, Agriculture, and Defense; (2) State representatives from Education and non-Education Part H Lead Agencies; (3) State preschool coordinators; and (4) parents of children with disabilities aged 12 and under.

Relationship of Legislative Mandates Among Member Agencies

The FICC, under statute, represents the major agencies responsible for payment and delivery of services to children with disabilities and their families. While the Department of Education, through the Office of the Assistant Secretary of OSERS, is charged with administering the IDEA, other Federal agencies have overlapping responsibilities related to the provision of resources and services for disabled children and their families.

For example, the Developmental Disabilities Act finds that, "individuals with disabilities occurring during their developmental period are more vulnerable and less able to reach an independent level of existence, and it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care." Title V of the Social Security Act directs Maternal and Child Health programs to provide "community-based, coordinated care for children with special health care needs with a focus on strengthening the family unit," and Title XIX of the Social Security Act (Medicaid) provides funds to enable States to provide "medical and rehabilitation services to help families and individuals attain or retain capability for independence."

These examples are parallel concepts to P.L. 102-119 findings that "there is a need to enhance the development of infants and toddlers with disabilities in order to minimize their potential for delay and maximize the potential for their independent living in society."

A joint study of the Federal funding sources and services for early childhood programs was mandated under the original legislation. This study and subsequent report found little or no coordination between the 16 identified Federal programs providing ongoing financial support to States for services to young children with disabilities. Consequently, Congress required that the Department of Education and the Department of Health and Human Services "jointly act to facilitate interagency coordination of Federal resources for such programs."

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ASSISTANT SECRETARY JUDITH E. HEUMANN

Judith E. Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services, U.S. Department of Education, has been a active for many years to gain legislative guarantees of equality of access and opportunity for people with disabilities. In 1974, she helped develop what became the Individuals with Disabilities Education Act. Subsequently, she helped draft the ADA, develop regulations for Section 504 of the Rehabilitation Act, and design federal and state legislation that led to the creation of more than 200 independent living centers nationwide.

The most significant goal for parents of disabled students is assuring that their children maintain the sense of self-esteem with which we are all born. Parents are their children's most important role model. If disabled children know that their parents have great expectations for them, they will have great expectations for themselves. If parents of disabled children encourage them to dream of a bright future, they will dream of a bright future, and work to achieve it.

My parents and hundreds of thousands of others waged a fight to open the school house doors for their disabled children. As a result of their hard work in coalition with many other groups, our nation adopted the Individuals with Disabilities Education Act.

Parents of disabled children have also contributed a lot toward helping the American education community recognize that all children can learn, if teachers use teaching techniques that meet students' needs.

I believe that the accomplishments of parents with disabled children will be viewed by history as reaffirming the fundamental right of all Americans to be free from discrimination and arbitrary treatment.

The fundamental goal of PTIs should continue to be creative effective partnerships between parents and between parents and educators. No one knows what children need to become effective learners better than the parents who love them. And no one knows how to help children reach their goals better than the teachers who teach them.

The Parent Training and Information Centers help parents become effective partners in the education of their children by giving parents the training and information they need to effectively exercise their rights and responsibilities under IDEA.

The IDEA empowers parents to be participants in decision-making about their children. In order to effectively carry out this critical role, parents need to know their rights and they need to be knowledgeable about programs and services.

What do I think are the most serious challenges the PTIs face today? Helping parents and school personnel overcome overlays of ethnic, racial, language and cultural differences to truly work together in ways that benefit students. For example, both parents and teachers are overworked, and the simple task of finding time to meet with each other can be daunting.

Parents of disabled children must continue working to assure that their children will have a future which is free from discrimination.

The strategies for achieving this goal are:

- Making sure that the needs of disabled children are included in the nationwide movement for school reform.
- Making sure disabled children have meaningful access to the general curriculum, with appropriate accommodations. The education received by students with disabilities should be aligned with the education received by non-disabled students. The educational opportunities given to all students should meet the same high standards.

Parents of disabled children must continue advocating for effective placement of their children, and for their children in assessments at the state and local levels. ◆

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CONGRESSMAN MAJOR OWENS

Representative Major R. Owens, Brooklyn, New York, served as Chair of the House Subcommittee on Select Education and Civil Rights from 1987 to 1995, where he led the reauthorization of IDEA in 1990.

Congressman Owens championed the establishment of the TAPP initiative to support and develop parent leadership in traditionally underserved communities.

The parent movement played a significant role in the creation of federal legislation to ensure that children with disabilities have equal access to educational opportunities, the landmark Individuals with Disabilities Education Act (IDEA).

The Parent Training and Information Centers authorized by this legislation play a critical role in enabling parents from various backgrounds to help their children with disabilities take advantage of the IDEA.

Parent Centers should continue providing parents with the services needed to help them make sure their children are receiving a free appropriate public education as mandated by the IDEA. Moreover, the Centers must work with parents and schools to prevent the misclassification of children who may not have learning disabilities or should not be classified as emotionally disturbed.

Parents must be especially vigilant during these uncertain times in closely monitoring the effects a reauthorization of IDEA legislation will have on kids who will be "included" in the school system. They must defend against "dumping" children with learning disabilities and emotional disturbance into the unified school environment without a proper IEP process and guaranteed continuum of services.

Parent Centers must also direct their energy to ensuring that teachers working with these children are qualified to provide the needed services. The persons providing related services must also meet the highest professional standards.

Parent Centers must address the system shortfalls that children in urban and rural communities get caught up in simply because parents do not have the opportunity to actually know what they are guaranteed under the law. We must never forget that the reason the Congress established Parent Centers was to ensure the active participation of parents in their children's education.

In today's Congress, funding for successful grassroots programs is imperiled by the appropriations process. During the reauthorization process, discretionary programs are in even more danger.

Today's danger is the lack of interest by some members of Congress in the rights of children from poor backgrounds. As a result, they will de-fund the very successful Parent Centers because Parent Centers provide knowledge. This knowledge is dangerous because then parents will begin to ask for their children's educational rights, including related services and assistive technology. If parents know their rights, Congressional members will be attacked for not providing money for these important services.

During the reauthorization of IDEA, I intend to introduce amendments to expand the number of parent centers and to ensure that children who are misclassified receive the support they need to be successful in the unified school environment. ◆

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Lou McIntosh is the father of two children with Cerebral Palsy, Alex 9, and Douglas 5. He lives in Dover, New Hampshire, with wife Laurie, who is a pediatric occupational therapist. Lou was instrumental in developing a statewide telecommunication network for parents and families in Maine, The Maine Meeting Place Project, which has been replicated in several other states.

States represented: Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, Puerto Rico, and the Virgin Islands

Thedia Michelle Gamble

P.O. Box 415
Chenle, AZ 86503

Thedia Gamble is a member of the Navajo tribe. She is the single mother of four children. Her daughter Kellynn has special needs. Currently, Thedia participates on Arizona's ICC Native American issues Subcommittee, the Navajo tribe's Community Advisory Council on Early Intervention (CEI), and its Administrative Council on EI. She will join the Navajo tribe's family support agency's Advisory Board, Reaching Harmony. She also sits on the Parent Advisory Board for a new grant that was funded by OSERS called Project SELF (Supports for Learning Foundation). She continues to present with the Arizona School for the Deaf and Blind on a training videotape and manual on providing culturally appropriate services to Native American children.

States represented: New Mexico, Utah, Wyoming, North Dakota, South Dakota, Colorado, and Arizona

Lawrence Steven Lopez

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Whittier, CA 90606
Phone: (562) 692-8616

Lawrence S. Lopez has been a public school teacher for twenty-one years. His teaching experiences include elementary, secondary, the community college level, as well as adult education. Curriculum experiences include music education, and English as a second language acquisition. In addition, he has for many years taught in a bilingual classroom. Currently, he is a fifth grade teacher in the Montebello Unified District. Lawrence and his wife reside in Whittier, California. They have three children, two of whom have special needs.

States represented: California, Nevada, Hawaii, Guam, and Palau

Sharon Barnhill

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Sharon Barnhill is a parent-professional trainer, an advocate, and a member of the Statewide Independent Living Council (SILC). She is the founder of South Side Parents of Children with Special Needs, and has been resource for families since 1991. Sharon is the parent of Neville (10), who has Down Syndrome, Tiffany (6), who has Cerebral Palsy and hyperactivity, and Jarrell (2), who has sensory integration challenges and is developmentally delayed. Sharon is the Federal Interagency Coordination Council Parent Representative and is on the Executive Committee. She is the Training and Information Coordinator for Illinois' New Parent Training and Information Center, Family T.I.E.S. and is the Statewide Project Assistant for Illinois Federation Families. Sharon Barnhill believes in Family Choice, and when families are fully informed, they are better advocates for their children.

States represented: Illinois, Missouri, Tennessee, Oklahoma, Iowa, and Arkansas

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FICC PARENT MEMBERS (cont.)

Marybeth Zahorchak

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Marybeth Zahorchak is the parent of a child with special needs. Her son Patrick is 23 months old. He was born with hydrocephalus and has a stroke inutero. This has resulted in total blindness and physical handicaps. They have been very involved with early intervention services in Pennsylvania.

Since July 1995, Marybeth has been employed by Hershey Medical Center as a family consultant. This has been funded by a grant from the Pennsylvania Department of Health. Marybeth works with the medical staff, families, and children with special needs to educate them on early intervention services, family professional collaboration and support.

States represented: Pennsylvania, West Virginia, Virginia, Maryland, Delaware, District of Columbia, South Carolina, and North Carolina

Tricia Benefield

5790 Hermosa Circle
Pensacola, FL 32526
Phone: (904) 453-8014

Trecia Benefield is married to Greg Benefield. They have two children: Mary Louise and Ashlee. Ashlee is a head injury victim. Trecia is an area Training Coordinator for the Family Network on Disabilities.

States represented: Florida, Georgia, Alabama, Mississippi, Louisiana, and Texas

Felicia Jordan Da-Silva

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Detroit, MI 48235
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(800) 359-3722
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Felicia Jordan Da-Silva is a Parent Consultant for the Michigan Department of Community Health, Children's Special Health Care Services. For the past seven years she has been working the organizing support groups, developing and providing training to parents and professionals of children with special needs in culturally sensitive settings.

Felicia is a parent of three children. Two of them have special health care needs, one with moderately severe asthma, and one with Cerebral Palsy.

Felicia served on Michigan's State Interagency Coordinating Council for five years and co-chaired the council for one year.

States represented: Indiana, Michigan, Wisconsin, Minnesota, Ohio, and Kentucky

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Pending Appointment: A representative for the following states: Washington, Oregon, Idaho, Alaska, Montana, Nebraska, and Kansas.

Until that appointment is finalized, parents may call Connie Garner, Executive Director of the FICC, (202) 205-8124.

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The Role of the FICC

The FICC serves as the vehicle for Federal agencies with common programmatic goals to: (1) facilitate coordination of resources at the Federal level; and (2) model interagency coordination at the Federal level, to State and local agencies, with the ultimate purpose of strengthening the service system for children with disabilities and their families.

The mission of the FICC is to work towards: (1) minimizing duplication across public agencies which provide services to infants and toddlers with disabilities and their families; (2) ensuring coordination of technical assistance activities across agencies supporting this population; (3) ensuring the provision of early intervention and preschool programs; (4) identifying gaps in programs and services across agencies; and (5) identifying barriers to cross-agency coordination of services to infants, toddlers and preschoolers with disabilities and their families.

Strengths of the FICC

- is the only interagency government body established in statute to address the needs of young children with disabilities and their families;
- has the national perspective and ten years of institutional memory for services to young children with disabilities and their families; and should serve as a model for federal leadership for systems for all young children;
- has investigated "hard issues" in the delivery of integrated services; dispute resolution using mediation strategies; balanced funding sources and managed health care;
- involves parents/consumers as members in all decision-making;
- has sponsored eight national conferences bringing the Early Childhood Community together.

Summary

The FICC is an entity which has and will continue to improve the coordination of services to children with disabilities and their families, as well as to the much larger group of children known to be at risk for developmental problems. As we approach the turn of the century with the goal of having "all children healthy and ready to learn," the multi-dimensionality of that vision requires interagency/interpersonal collaboration and decision-making.

Over the past three years the statutory FICC, comprised of parents, professionals, and policy-makers has been given the time to ecologically incorporate change and build the interagency relationships so important to this goal of collaboration.

The evolutionary process continues as we move into this new era of state and Feral partnerships, where the FICC can be a vehicle through which systems change can result in a better quality of life for children with disabilities and their families.

FICC Parent Generic Workplan

The purpose of the workplan is to frame and guide the role of the FICC parent using a State and regional approach. Through negotiation with state leaders in the early childhood programs, it is our intent that the FICC parents will craft workplans that:

(1) strengthen communication and dissemination of information between the Federal ICC and State ICC's;

(2) offer support and technical assistance to ICC parents as requested; and,

(3) facilitate timely identification of interagency policy issues related to the early childhood programs to the Federal Interagency Coordinating Council.

Mission Statement

To bring issues to the FICC which are important to children and their families; bring information to the regions and the diverse communities about the activities of the FICC; and advocate for policies which support positive outcomes for children and their families.

Outcome #1: Promote awareness of FICC and SICC activities and of Early Intervention services through participation on the FICC, and ensure that the parent/family perspective is represented effectively in Federal Early Intervention policy.

Outcome #2: Work to improve the quality of parent participation in the activities of State ICC's through information sharing, networking, and mentoring of SICC Parent Representatives.

Outcome #3: Inform and empower parents so that they may participate constructively in state and local Early Intervention System activities and be more effective partners in improving delivery of Early Intervention Services.

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SICC Parents Speak Out

*The SICC parents met Friday morning, November 10, 1996 at the NEC*TAS Combined Meeting and discussed what they needed to learn this year in order to do their job as parent representatives on the SICC. Ruth-Ann Rasbold led this focused discussion and organized the expressed needs into several categories. The NEC*TAS staff will consider these expressed needs and make plans on how best to respond to them, such as through future issues of the Early Childhood Bulletin, through teleconferences open to all ICC parents, and by infusing these needs into the meetings sponsored by NEC*TAS and the written products in the next year. The ICC Parent Leadership Project, housed at the Federation for Children with Special Needs in Boston, will also consider these expressed needs in determining what to include in the modules that are being developed.*

What do I want/need to learn this year in order to do my job as a parent representative on the SICC?

Experienced and novice parents serving on state Interagency Coordinating Councils gave a variety of responses to this focus question. Most of the answers fell into the following categories: Involving Families Globally (networking); Activating Parents 101; Activating Parents 202; Communicating and Training; and Other Issues.

- **Involving Families Globally.** Parents want to get information from other parents, and get information to families across their state, and across the country. There was a lot of discussion about how to keep people involved, how to establish connections with other local and state ICCs, and how to build connections among all parents on the council.
- **Activating Parents 101/ Activating Parents 202.** Several tasks were identified by parents serving for the first year, and other tasks were identified by parents serving for several years. In 101, most of the emphasis was on understanding the role of ICC parents and understanding everyone else's role on the ICC. Parents asked for help in identifying and discussing these roles.

  After the first year of service, more complex issues emerged. The topics included: how to ask for money without guilt; how to approach a legislative body; understanding funding / Part H budgets in a family-friendly way; time management; developing a better understanding of the state political system.
- **Communicating/Training.** All the parents felt there was a need for ongoing training in leadership and mentoring, and for increased emphasis from parent training and information centers on issues of importance to children under five. The participants in the focus group identified newsletters and conferences as invaluable resources for finding out what is happening in other states and regions.
- **Other issues.** Several other single issues were identified by parents which NEC*TAS staff have heard over the years: How do states reimburse parents for serving on their advisory council? What kind of orientation do states provide for parent members of the ICC? for all members of the ICC? Are there parent representatives serving on monitoring teams (local, state, federal)?

Staff from NEC*TAS and from the ICC Parent Leadership will continue to explore ways of responding to these requests for technical assistance.

NEC*TAS

is sponsoring two conference calls for ICC parents

Monday, July 7 — 1:00 PM EDT
Thursday, September 19 — 1:00 PM EDT

Information will be sent to all
SICC parents in May.
Call Kim Brame at NEC*TAS for more information
@ (919) 962-2001

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